FR Doc 04-11365
[Federal Register: May 20, 2004 (Volume 69, Number 98)]
[Notices]
[Page 29139-29140]
From the Federal Register Online via GPO Access
[wais.access.gpo.gov]
[DOCID:fr20my04-52]

I am 62 years old, congenitally visually-impaired (near-blind) and was diagnosed with diabetes 5 years ago. My husband is 71 years old and now totally blind from retinitis pigmentosa. I have worked for nearly 23 years as a rehabilitation specialist with people who are blind and visually-impaired. I cannot give exact numbers but can give some fairly well-educated estimates and information based on experience.

Demographics:

66% to 75% of my clients are age 55+
Onset for the majority is 50+
Referrals: age related macular degeneration, diabetes, or stroke.
Most report at least minimal hearing impairment, but few are not able to understand the spoken word
Most have multiple disabilities or health problems and understand them fairly well
Represent all socio-economic levels
Most are able to make simple adaptations but are frustrated by, or resistant to, complex technology
Younger referrals often show cognitive involvements.
Among those age 75+, more problems with short term memory are apparent
Different techniques and technology might be appropriate for individuals with cognitive or memory impairments and those with hearing impairments that prevent them from understanding the spoken word. Some individuals do best with non-visual (blindness) techniques.

Use of Prescription Medication Information

1. People tell me they have the pharmacist tell them how to use their medications. Then they take them home and have a friend or family member read the labels and help them know they are taking the right medications at the right times. Many have a health aide or home care attendant organize medications into compartmentalized trays. Some try to mark containers with black markers. A few put raised markings (tactile paints) on lids or labels. Others store medications according to time of day for use and/or in locations where they are most likely to

2004N-0221
C 4

use them. We tried an audible prescription program, but it was a mail-order program and we had concerns about how well our orders were filled. The labels and label reader worked quite well. Other audible labels are not readily reusable and, though individually inexpensive, require a label for each container and would be quite expensive for the person taking numerous medications. Others use their CCTV systems.

2. Containers are small. Pharmacies print labels that fit the containers. The print is necessarily small. Many visually-impaired people can read large print, even if they must put it very close to the eye. But they may not be able to read it accurately as they believe they can. If the individual does not hear well, it is possible for them not to fully understand verbally-provided instructions. If they have recall difficulties, they may not remember instructions well. These people have often learned to rely on writing down information to help themselves. They often can learn a pattern after several repetitions of it, but they must be closely monitored during the learning process.
3. Computers can enlarge and print many things. If pharmacists could print enlarged labels, this could help numerous visually-impaired people. A system such as the Aloud audible labeling system could be set up so that pharmacists could record and attach labels to prescription containers and consumers could have a label reader in the home to read the labels. This was the unit we tried, but we had to use the mail-order facility, and we were not comfortable with their handling of our prescriptions. If local pharmacies could provide this type of service, it would be a major help. Braille could also be a benefit to many blind persons. However, the technology to produce braille labels and the bulk of braille might create some difficulties. We are braille users; but the majority of blind/visually-impaired persons are not.
4. I have found that most people work out a system of medicinal management and stick to it. I have found few errors among my clients. We have, however, had two personal experiences with home health aids assisting my husband in setting up his medicines after hospitalizations. The home health aides did not understand the system we had developed and rearranged his medications to their liking. This confused both my husband and me. Confusion after severe illness is the problem I've seen most.

Technology:

1. Most of the people I see neither have nor use technology other than a CCTV to access prescription medicine information.
2. Those who use CCTVs are generally from the higher socio-economic stratus or those with incomes low enough to qualify them for assistance from a program that

can make loans. The availability of equipment is minimal. Most of those who do not use CCTVs do have Medicare, which does not provide CCTV equipment.

3. In addition to the reading of prescription medication labels, the CCTV has numerous uses that allow the user to retain or regain a good deal of independence. The CCTV allows users to read and pay bills, handle mail and correspondence, read recipes and nutrition information on packaging, and (sometimes) to read for pleasure. The audible system we tried did allow more independence because my husband did have the ability to check each medication container and know that he was getting what he needed.
4. Both the CCTV and audible label system allow people to verify that they are taking their medications properly and reduce the amount of assistance they require. In some cases, it can make the difference between their having to have a paid attendant or not, thus reducing the overall cost of support services.
5. The cost of a CCTV ranges from about $1,000 and up. The audible label reader we used was $100. I don't know the cost of the recorder, but a pharmacist could use one recorder to assist numerous customers.
6. Consumers must generally purchase their own equipment. In this area, to my knowledge, CCTV's are provided through the Older Individuals who are Blind program if the consumer meets economic need guidelines. Supplies are limited. Vocational Rehabilitation may provide a CCTV for a consumer who will be employed. I know of no one who provides audible prescription labels and no local pharmacy that can make anything available.
7. The major barrier is cost. People can be placed in programs to provide paid attendants to help them manage their medications at (last I knew) $110/hr). Consumers generally don't come off these programs and tend to lose confidence and learn dependence. After a few short weeks, a CCTV will have paid for itself by allowing its user to maintain independence in the area of medicinal management – not to mention the independence in the other areas mentioned.
8. A wide variety of CCTV's is available. Most low vision specialists show them to consumers and often recommend them. The snag comes when the price tag is divulged and the consumer cannot cough up $1,000 or more for the equipment and doesn't meet economic need guidelines for the local program. The audible labels are less well known. The less expensive are cumbersome and become expensive in the long run. Pharmacies are not set up to use them.
9. Word of mouth is common. People tell one another about products they like. A few products are generally advertised. Products are commonly advertised in professional blindness literature. Some is written up in consumer publications. Low vision specialists and professionals in the field of blindness also discuss these technologies. Fewer individuals are dissatisfied with CCTVs if they have had the opportunity to try one, so contact with a blindness professional or low vision

specialist is recommended. Audible labels are also advertised in blindness publications. I am not aware of their being demonstrated by other than blindness professionals.

10. I have learned of nothing more available or versatile than the CCTV or the audible prescription labeling system described above.

Nancy Johnson
714 SW Wayne Avenue
Topeka, KS 66606-1753
May 29, 2004